

ICO consultation on the draft updated data sharing code of practice

Data sharing brings important benefits to organisations and individuals, making our lives easier and helping to deliver efficient services.

It is important, however, that organisations which share personal data have high data protection standards, sharing data in ways that are fair, transparent and accountable. We also want organisations to be confident when dealing with data sharing matters, so individuals can be confident their data has been shared securely and responsibly.

As required by the Data Protection Act 2018, we are working on updating our data sharing code of practice, which was published in 2011. We are now seeking your views on the [draft updated code](#).

The draft updated code explains and advises on changes to data protection legislation where these changes are relevant to data sharing. It addresses many aspects of the new legislation including transparency, lawful bases for processing, the new accountability principle and the requirement to record processing activities.

The draft updated code continues to provide practical guidance in relation to data sharing and promotes good practice in the sharing of personal data. It also seeks to allay common concerns around data sharing.

As well as legislative changes, the code deals with technical and other developments that have had an impact on data sharing since the publication of the last code in 2011.

Before drafting the code, the Information Commissioner launched a call for views in August 2018. You can view a summary of the responses and some of the individual responses [here](#).

If you wish to make any comments not covered by the questions in the survey, or you have any general queries about the consultation, please email us at datasharingcode@ico.org.uk.

Please send us your responses by **Monday 9 September 2019**.

Privacy Statement

For this consultation, we will publish all responses except for those where the respondent indicates that they are an individual acting in a private capacity (e.g. a member of the public). All responses from organisations

and individuals responding in a professional capacity will be published. We will remove email addresses and telephone numbers from these responses; but apart from this, we will publish them in full.

For more information about what we do with personal data please see our [privacy notice](#).

Questions

Note: when commenting, please bear in mind that, on the whole, the code does not duplicate the content of existing guidance on particular data protection issues, but instead encourages the reader to refer to the most up to date guidance on the ICO website.

Q1 Does the updated code adequately explain and advise on the new aspects of data protection legislation which are relevant to data sharing?

- Yes
- No

Q2 If not, please specify where improvements could be made.

As a movement of patients, relatives and carers, we recognise that we are clearly not the primary audience for this document.

Q3 Does the draft code cover the right issues about data sharing?

- Yes
- No

Q4 If no, what other issues would you like to be covered in it?

Given the need for increased levels of transparency as a means to improve public/patient trust in how their data is used, we have approached this from the perspective of a patient wanting to understand more about how their data is protected and used.

Are there any plans to produce something like this, but with a specific patient focus? Given that all data controllers have to produce information for patients, would it not be sensible to produce some central guidance in this area?

Q5 Does the draft code contain the right level of detail?

- Yes
- No

Q6 If no, in what areas should there be more detail within the draft code?

Sometimes less is more. Whilst we recognise the need for completeness in this complex area, there may be a benefit in a more navigable route through this complexity.

So whilst the draft appears to be comprehensive, and all the information appears to be in there, it might prove difficult in practical use.

Have you considered some form of flowchart or decision-tree which could allow organisations to navigate to the areas which are relevant to them?

This might also be useful for a patient audience.

Q7 Has the draft code sufficiently addressed new areas or developments in data protection that are having an impact on your organisation's data sharing practices?

- Yes
- No

Q8 If no, please specify what areas are not being addressed, or not being addressed in enough detail

Q9 Does the draft code provide enough clarity on good practice in data sharing?

- Yes
- No

Q10 If no, please indicate the section(s) of the draft code which could be improved, and what can be done to make the section(s) clearer.

From a patient perspective, the area of uses of anonymised or pseudonymised data remains confusing.

Whilst truly anonymous data can be put in the public domain, understanding what use is made of our de-identified data (by this we mean anonymised or pseudonymised) remains much less clear.

We would have hoped for clarity around how our de-identified health data can be used where the National Data Opt-out does not apply. We are aware that websites exist, produced by privacy groups, which show that organisations have received de-identified health data which includes data on patients who have requested to be included in the National Data Opt-out. This is breeding confusion and mistrust.

Finally, on the topic of the word “sold”, we would like the ICO to be much clearer about whether cost-recovery should be regarded as “selling data” or not.

Q11 Does the draft code strike the right balance between recognising the benefits of sharing data and the need to protect it?

- Yes
- No

Q12 If no, in what way does the draft code fail to strike this balance?

The focus of the Guide appears to be about the mechanistic and procedural elements of sharing data, rather than on the benefits which may be accrued.

We would also highlight that there are potential harms which could occur if data is NOT shared. This factor is mentioned briefly only twice in the document but should also be taken into account and given a more prominent emphasis.

Q13 Does the draft code cover case studies or data sharing scenarios relevant to your organisation?

- Yes
- No

Q14 Please provide any further comments or suggestions you may have about the draft code.

Q15 To what extent do you agree that the draft code is clear and easy to understand?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Q16 Are you answering as:

- An individual acting in a private capacity (e.g. someone providing their views as a member of the public or the public)
- An individual acting in a professional capacity
- On behalf of an organisation
- Other

Please specify the name of your organisation:

use MY data - www.useMYdata.org.uk

Please contact [REDACTED] if you have any queries about our response.

Thank you for taking the time to share your views and experience.